

## RESEARCH

# Increased Agency through Screens and Co-Creation – Literacy Practices within a Group of People with Aphasia at a Swedish Folk High School

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This article aims to analyse characteristics of collective and authentic literacy practices within a group of people with aphasia attending an aphasia course at a Swedish folk high school. The group included 12 individuals with aphasia who were studied during a period of 3 weeks. Ethnographic data consists of video and audio recordings, photos and field notes. Two main characteristics of the literacy practices were identified: digital screens dominated and bridged the online/offline boundary, and shared knowledge enabled the participants to co-create literacy. The literacy practices were emancipatory, because they provided ways for the participants to un-mask their inherent competence, increasing their agency. When the use of digital technology transforms a (formerly non-literacy) practice into a multimodal literacy practice, and when an individual with aphasia becomes part of a literacy co-creation practice, the disability (understood as a relation between individual and environmental characteristics) caused by aphasia is reduced.

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**Keywords:** aphasia; literacy practices; multimodality; agency; disability; ethnography

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## Introduction

This article reports findings from an ethnographic study about literacy practices within a group of people with aphasia (i.e., communicative difficulties caused by a brain injury, such as stroke) attending a Swedish folk high school (FIN 2016) aphasia course designed to provide an opportunity to improve abilities to engage in social interaction. Kagan and Simmons-Mackie (2013) define aphasia as a language problem that

masks inherent competence and most dramatically affects conversational interaction (talking and understanding), as well as the ability to read and write.

As highlighted in this definition, aphasia entails being unable to express competence. It is still there (it is inherent), but it is masked by linguistic difficulties. This masked competence may be understood in terms of a reduced 'capacity to act', i.e., reduced *agency* (Brockmeier 2009). People with aphasia often struggle with an identity dilemma of agency (Bamberg 2011). On the one hand, they are still competent, but on the other, they are often perceived as 'stupid', 'slow' or even 'drunk' (Taubner, Hallén & Wengelin 2019) because of their difficulties speaking. But aphasia not only affects spoken language. It also affects the ability to read and write i.e., literacy skills.

Literacy has traditionally been viewed as a set of reading or writing skills. However, over the last decades this perspective has been challenged by the theory of *literacy as social practice* in which literacy is considered to be a 'community resource, realised in social relationships rather than a property of individuals' (Barton and Hamilton 2000: 13). This shift means moving from a deficit perspective, in which people with language disabilities such as aphasia are assessed based on their lost skills rather than on their abilities, to a practice perspective in which people are studied based on what they actually do with text in their social contexts. This combination of individual abilities and social factors adheres to the relative model of disability in which disability is defined as being a gap 'created in interaction between individual and environmental characteristics' (Söder 2013: 102). Thus, without ignoring the actual language loss of aphasia but focusing on social practices in which people with aphasia engage, this study draws on the relative view of disability and on the theory of literacy as social practice.

Central to the theory of literacy as social practice is the interplay between *literacy events* and *literacy practices*. Literacy events are 'observable episodes which arise from practices and are shaped by them' (Barton and Hamilton 2000: 8). Literacy practices are 'the general cultural ways of utilizing literacy that people draw on in a literacy event' (Barton

and Lee 2013: 12). Thus, literacy events simultaneously shape and are shaped by literacy practices. Literacy practices are impossible to observe; therefore, research about literacy practices focuses on finding patterns among observable literacy events to reveal characteristics of the practices. Metaphorically, the events are pieces of a jigsaw-puzzle and not until we put them together does the picture (i.e., the practice) become visible.

To interlink literacy events and practices, Vuorenpää (2016) introduced the concept of *literacy chains* as a meso-level between them. Such (observable) chains can, in contrast to isolated events, consist of actions performed over a longer period of time and include more people. To revisit the jigsaw puzzle metaphor, literacy chains are clusters of pieces put together before being incorporated into the main puzzle. They do not reveal the entire picture, but they are bigger units than the isolated pieces.

In parallel with the development of the theory of literacy as social practice, the work of scholars like Kress (2003, 2010) has transferred literacy research into the digitalised 21st century by addressing issues of online multimodality and the increasing importance of screens (instead of print). The boundaries between offline and online practices, as well as between spoken and written language, are blurred (Barton and Lee 2013). In Sweden, this development has led to almost the entire population being internet users (Swedish Internet Foundation 2018). We, now more than ever before, live in a 'textually mediated world, where texts are part of the fabric of social life' (Barton and Lee 2013: 11).

Despite the importance of literacy in contemporary Western life, there are few previous studies about literacy practices and language disabilities such as aphasia. Among them, Parr (1995) argues that literacy practices need to be addressed within aphasia rehabilitation. Garcia Obregon (2002) studied the literacy practices of one specific person with aphasia, concluding that literacy had an important and complex role in his life. Kjellén, Laakso and Henriksson (2017) interviewed 12 individuals with aphasia and concluded that literacy was an ongoing recovery process for them. None of these studies include groups of people with aphasia, as does this current study, nor were they based on ethnography.

Although ethnography has been argued to be an important and valid way to study social aspects of living with a communication disorder in general (Hendryx-Bedalov 1998; Kovarsky 2016), as well as aphasia in particular (Simmons-Mackie & Damico 1999), only a few ethnographic studies exist about groups of people with aphasia. Among them are Antelius (2009), who studied communication within a group of people with acquired brain injuries at a day centre, Sherratt and Simmons-Mackie (2016), who studied shared humour in a long-standing social participation aphasia group and Tregea and Brown (2013), who studied peer-led support groups for people with aphasia. There are, in addition, some ethnographic studies about single individuals with aphasia and the authentic situations and contexts (in which they are the only ones with aphasia) of their everyday life (e.g., Davidson, Worrall & Hickson 2003; Legg & Penn 2013; Parr 2007). All of these studies focus on oral rather than written communication, as opposed to this current study. Yet other studies (e.g., Horton, Lane & Shiggins 2016; Simmons-Mackie et al. 2007) do include groups of people with aphasia but focus on clinicians or therapy methods rather than the individuals with aphasia.

In contrast, this current article is based on ethnographic participant observation within a group of people with aphasia attending an aphasia course at a Swedish folk high school. The aim is to analyse literacy practices (manifested as observable literacy chains) within the group. The aim is narrowed only to include literacy practices that are collective (i.e., involving more than one group member) and authentic (i.e., spontaneously occurring outside the classroom without influence of a teacher). Hence, the research question is: what are the characteristics of the collective and authentic literacy practices of a group of people with aphasia attending an aphasia course at a Swedish folk high school? Drawing on the idea that aphasia 'masks inherent competence' (Kagan & Simmons-Mackie 2013), the findings will be discussed in terms of agency.

## Method

To study literacy practices within a group of people with aphasia, I conducted ethnographic research based on a high level of participation (Spradley 2016). Ethnography provides tools for observing literacy events (and chains) over time to identify literacy practices, and it is therefore closely related to literacy research (Street 2004). I spent three weeks with the group at the folk high school, collecting data through a variety of methods.

### *Setting and participants*

The group consisted of 12 people enrolled in an aphasia course at a Swedish folk high school. The aphasia course was based on two seven-week periods each semester, with a four week leave in between. Students were enrolled for one semester at a time. They could choose to stay at the school during the weeks or to stay at home and spend the days at the school. Four classes were scheduled each day, ranging from reading aloud together to basic maths and individual computerised language practise.

No medical records were gathered about the participants (see also Parr 2007; Tregea and Brown 2013), neither were any formal assessments made to establish their level of aphasia. Being enrolled in the aphasia course was deemed sufficient as inclusion criterion. The characteristics of each group member are presented in **Table 1**.

A few teachers, other staff members and visitors were also included in the data collection. Because they are not the focus, no further details about them are presented here.

**Table 1:** Characteristics of the participants.

Alias	Gender	Age	Time since stroke (y.m)	Current semester at the school	Staying at the school
Anders	Male	31	1.9	2	No
Anette	Female	52	5.8	2	Yes
Claes	Male	73	3.1	2	Yes
Dennis	Male	68	2.11	4	Yes
Joakim	Male	55	4.5	7	Yes
Kalle	Male	65	8.2	2	Yes
Maria	Female	51	3.8	6	Yes
Ove	Male	57	2.5	2	Yes
Per	Male	45	1.8	2	Yes
Pia	Female	60	2.9	1	No
Selena	Female	60	2.10	2	Yes
Ulla	Female	83	2.6	2	No

**Procedure and data collection**

To gain ‘access to the field’ (Hammersley & Atkinson 2007), I contacted the head teacher of the aphasia course. She put me in contact with her superiors to get their consent to let me conduct my research at the school.

I visited the group twice before ‘entering the field’ (Hammersley and Atkinson 2007). During my first visit (five weeks before entering), I informed the group about my research and spent a couple of hours with them. They also received written information, including contact information. One week before entering, I visited the group again to get their written consent to participate.

To conduct the data collection, I stayed with the group at the school for three weeks (except weekends). I spent my days as if I were a student at the aphasia course: staying in one of the rooms in the same hallway as they did, eating the same food, taking part in class (although not actively in all activities), watching the same television shows and joining them for walks or other leisure activities. I spent as much time as possible with the participants, observing them and, when needed, making short informal interviews with them. I constantly kept a notebook and a camera with me to make annotations or to take photos when something caught my attention.

When studying people with aphasia or other communication disorders, video recording may be crucial to capture the alternative strategies they might use (gestures, writing, drawing, etc.). As Strandroos and Antelius (2017: 541) conclude: ‘video recordings has enhanced the data, since it is hard to capture all the richness and expressions of a communicating body, relying on observations alone’. During the first week, I captured video and audio solely in the classroom.

As time went by, and as I experienced increased trust from the participants, I extended my field work to include more data collection methods and more settings. During the second and third weeks, I video recorded the interactions in the television lounge where the group usually gathered after dinner. The lounge, situated in close relation to their individual rooms, was specifically created for the aphasia course attendants. The video camera was placed so that everyone seated was captured but not the television screen.

During the third week, I added audio recording during coffee or meal time. It turned out to be difficult, because there were others (who had not given their consent) present and the acoustic environment was disadvantageous.

The data collection resulted in a large amount of data, including more than 40,000 words of field notes, around 200 photos and approximately 15 hours of video from outside the classroom (and an additional 60 hours from the classroom, which is not included in this article) and an additional 5 hours of audio.

About 14 weeks after ‘exiting the field’ (Hammersley & Atkinson 2007), I went back to the school for a final meeting with the group, to report back to them and to validate some of my preliminary findings through ‘respondent validation’ (Hammersley & Atkinson 2007).

**Analysis**

I started analysing the collected data immediately and recurrently, by constantly writing down my reflections and possible interpretations, as suggested by Hendryx-Bedalov (1998). After the field work was finished, an intense analysis period followed.

Coding was performed using Nvivo 12 Plus, initially based on the date (e.g., Monday of week 3), activity (e.g., breakfast), location (e.g., canteen) and participants (each participant was coded as a separate case). I then searched the material (video

recordings, field notes and photos) for literacy events. When I identified an event in a video recording, I transcribed that sequence in as much detail as possible, including visual information and verbally expressed communication. Because most of the audio recordings overlapped the video recordings, and because I did not find anything in the field notes indicating a need for further analysis of the audio recordings, I neither transcribed nor analysed them.

I identified literacy chains, which I coded as 'stories', including all types of data related to that particular story. Thus, each story contains events performed by different people during a certain amount of time.

As the coding proceeded, I added codes to describe emergent patterns (practices), or in the words of Hammersley and Atkinson (2007: 162) I searched for concepts to help me 'make sense of what is going on in the case or cases documented in the data'. Those concepts were changed continuously to match new findings, and new codes were added when needed. Finally, I worked through the material again to ensure that everything was correctly coded, and I corrected any inaccuracies.

Ethnographic analysis 'is not just a cognitive activity but a form of writing' (Hammersley and Atkinson 2007: 190) through which the ethnographer develops a deeper understanding for the studied community. Throughout the research process, writing takes different roles. At first, the written text comprises field notes, and subsequently, the writing gets increasingly abstract, until the final product (i.e., the ethnography itself) is formulated (Hendryx-Bedalov 1998). The process of this study was no exception. Field notes, inferences (interpretations of the field notes) and methodological annotations were produced during my time at the school. For my follow-up visit, I wrote memoranda to read to the participants. While coding the material, I wrote memos about emerging key terms and how they were clustered into themes. Finally, I wrote an extensive text (the ethnography itself), part of which was then shortened down to become this article.

Although these steps may seem like a linear process, they are in fact intertwined in an iterative process, not only in terms of actual writing but also in terms of constantly combining writing with further analysis of data. In this sense, the analysis may be described as an abductive (i.e., combining data driven and theoretically driven processes) constant comparative analysis (Fram 2013).

### ***Ethical considerations and approval***

Written consent was obtained from all participants (including all affected teachers and staff members and visitors), separately for recording video, recording audio, writing field notes and taking photos. The participants were carefully informed that the choice to participate was voluntary and individual and that they were free to refrain at any time.

As Sherratt and Simmons-Mackie (2016) highlight, people with aphasia are often 'accustomed to being recorded' because they have spent a great deal of time in rehabilitation settings where video recording may have been used 'for quality improvement and educational purposes' (1044); therefore, it may be unexpectedly easy to gain consent for video recording. On the other hand, for the same reason, people with aphasia may be tired of being studied and recorded, which may lead them to oppose. For this study, all participants willingly gave their consent to all types of data collection. To respect the participants' privacy, I collected data only in communal spaces and not in any of their private rooms nor in any restroom.

Communicative adaptations may be necessary for the participants to be able to give their consent (Legg & Penn 2013; Parr 2007); therefore, verbal rather than written consent must be considered feasible, and when needed, specifically designed materials may be used. In this study, no such adaptations were necessary. However, later on during the data collection adaptations were made to meet the communicative needs of the participants (see also Tregea & Brown 2013). Such adaptations may include 'talking slowly, in short sentences, and supporting speech with key gestures, written key words, and pictures, including maps, timelines and scales' (Legg and Penn 2013: 130). On the other hand, there is a risk of being perceived as patronising if these adaptations are exaggerated. Thus, I tried to be receptive to each participant's needs and preferences. Overall, I made an effort to build a respectful and honest relationship with each participant (including staff members) to make sure they would trust me enough to tell me if anything felt uncomfortable.

In this article, all names have been changed to assure anonymity. Because there are only five Swedish folk high schools with specific long-term courses for people with aphasia (and a few with shorter courses), the name and the location of the school are not revealed.

Ethical approval for this study was granted by the Regional Ethics Committee in Lund, Sweden (ref 2017/793).

### **Findings**

The findings are presented as literacy chains, which are representative of the literacy practices of the group. These episodes are not the only occurrences but examples of practices with two main characteristics:

- digital screens bridged the online/offline boundary
- shared knowledge enabled co-creating literacy.

After the presentation of the three selected literacy chains, these identified characteristics of the literacy practices are elaborated.

**Chain 1: Co-creating a Facebook post**

A couple of times, I joined some of the participants to a nearby gym. At one of these occasions, we saw a man hanging in a safety harness from a tall building, doing some repair work on an antenna. Anette was impressed and took a photo of him with her phone. The next morning, during breakfast, Anette decided to post the photo on Facebook.

Anette creates a Facebook post about the man we saw yesterday (when we went to the gym in [small town]) hanging in a safety harness on a tall building. She took a photo then, and now she's going to share it. She writes a small caption to the picture, like this (as accurate as I can recall it):

“Yesterday when we went to [small town] to work out a [gym], we saw a guy hanging in a harness to fix an antenna I think really up high.”

It takes a while for her to write and she seeks my guidance with some spelling issues and because I was there. For example: what is the name of the thing he was hanging in? (Harness, I reply).

Joakim wants to see the result and reaches across the table to grab Anette's phone, and she gives it to him. He says (with great effort): “I am the proof-reader.” He opens the Facebook post to be edited and adds a ‘t’ to the word ‘at’ which Anette had missed. He also considers changing a few other things but gets unsecure and asks me. When he is satisfied, he returns the phone to Anette.

Anette wants to add an emoticon too, to show that she thought it looked scary to be hanging up there. Selena, who sits next to her, looks at her screen and they talk about which emoticons are available (isn't there one with a man climbing a ladder?). Eventually, Anette chooses an emoticon and sends the post.

**Excerpt 1:** Field note, Wednesday of week 2, breakfast in the canteen.

**Chain 2: Conversation about medication**

While watching television, Anette and Joakim once discussed medication against muscle spasms. Joakim wanted to tell me the name of his medication (Baclofen). He could not say the name, so he looked it up online (using his smartphone) and then wanted Anette to read it aloud to me. She started reading about the medication from Joakim's phone. They sat close to each other, leaning together, both looking at the screen. Between them and me, Dennis was seated.

Line	Timespan	Content	Agent
60	38:36,8–38:38,3	[Reads from Joakim's phone which she holds in her hand] Half a pill, is it?	Anette
61	38:38,3–38:39,1	Yes.	Joakim
62	38:39,1–38:40,6	'Half a pill three times a day'	Anette
63	38:40,6–38:44,2	Yes. But tell her... [points at me]	Joakim
64	38:44,1–38:45,8	Does it help? [referring to the medication]	Anette
65	38:45,7–38:49,3	Gah! TELL [points at me with his entire arm] her!	Joakim
66	38:49,2–38:50,3	What shall I tell...?	Anette
67	38:50,3–38:53,4	It. That. [points at the screen, still held by Anette, and draws with his finger as if to underline a part of the text]	Joakim
68	38:53,3–38:55,2	[laughs] Do you want me to read that aloud?	Anette
69	38:55,1–38:56,3	Yes, yes, yes. But...	Joakim
70	38:56,3–39:06,4	Bac/lo/feen/am...fa los... [gives up, laughs, gives the phone to Dennis for him to pass it on to me] You read it yourself!	Anette
71	39:06,4–39:09,5	[Dennis takes the phone from Anette and passes it on to me]	Dennis
72	39:09,4–39:17,1	[I accept the phone from Dennis and start reading on the screen]	Me

**Excerpt 2:** Transcribed video recording, Thursday of week 2, evening in the television lounge.

**Chain 3: Sending a postcard**

One staff member (here named B) had recently gone on sick leave, and the group missed her. Anette came up with the idea to send her a postcard. She and Joakim created a postcard using an online service (that results in an actual printed postcard being sent).

Joakim has an ipad on his lap. [...] He has opened the 'Real postcard' website, and gives the ipad to Anette. She scrolls around among the alternative postcards and wonders why there are only cards about love. I can see that there is a menu where that can be changed (it now says Valentine's day) so that other categories are displayed, and together we find the right category there. I understand that they are planning to send a postcard to B [...]. They laugh about the idea of sending her a card with the wrong kind of text (like condolences or forgive me), and blame the aphasia for not being able to choose the right card.

**Excerpt 3:** Field note, Tuesday of week 1, evening in the television lounge.

Almost a week later, I went for a walk with a teacher (here named A). She told me that B had received the postcard and posted a photo of it on Facebook.

A told me, during our walk, that B got a postcard from the participants [...] and she made a thank you post on Facebook and tagged [the group members with Facebook accounts, ie almost everyone].

**Excerpt 4:** Field note, Monday of week 2, afternoon break.

Later that day, at dinner, Selena was using Facebook on her smartphone and I saw the postcard on her screen. I asked the group what they wrote on the card. Joakim called B to ask her about the text they wrote. She took a photo of the card and sent it to Joakim for him and the others to see the text.

Selena has Facebook open and I see that the photo of the card, that B posted and tagged the participants in, is displayed there. [...] I ask about B and the card they sent to her. I wonder which card they eventually picked and what they wrote. They don't really know, don't remember. Eventually, Joakim calls B on the phone and talks to her. Everybody says hi to everybody and Joakim talks to her for quite a while. She also sends him a photo of the back of the postcard so that they could see the text they wrote. (It is a lovely text where they offer to come and pick her up if she wants to come and visit.)

**Excerpt 5:** Field note, Monday of week 2, dinner.

Even later, when watching television in the lounge, Selena wants to read the text of the postcard on the photo B sent to Joakim. He gives her his phone for her to read.

Line	Timespan	Content	Agent
19	17:32,9–17:45,3	[Joakim pulls out his smartphone from his pocket. He scrolls to something and gives the phone directly to Selena who takes it.]	Joakim
20	17:45,3–18:10,1	[Selena takes Joakim's phone and starts reading aloud.] "Hi. We think of you and miss you. Wonder how you are doing. You are welcome to come visit someday. We can pick you up. In that case, let us know. Lots of... Here comes lots of love from us at the aphasia course." Really nice! [Returns the phone to Joakim.]	Selena
21	18:10,1–18:11,6	Eh, ye, yeah.	Joakim

**Excerpt 6:** Transcribed video recording, Monday of week 2, evening in the television lounge.

A few days later, B came to visit the group.

### **Characteristics of the literacy practices**

As mentioned above, the findings indicate the following two main characteristics among the literacy practices of the group: digital screens dominated and bridged the online/offline boundary, and shared knowledge about each other's (dis)abilities and access to communication resources enabled the participants to co-create literacy.

#### **Digital screens bridged the online/offline boundary**

Almost every literacy event which the group engaged in outside the classroom included digital screens (smartphones, tablets, computers, smart watches or television screens). All three literacy chains related above show screens are central to literacy within the group. These chains are not unique, but rather examples of a pattern. Even Ulla, the only participant without a smartphone or tablet of her own, engaged in (and sometimes initiated) literacy events including screens.

During my follow-up visit, I asked the group about their post-stroke experience with writing by hand. Joakim then answered (laughing) that they only wrote by hand when forced by the teacher (here called A). Some said they used pen and paper to write shopping lists (although others said they used their phones for that purpose too), but because they did not shop while they stayed at the school, those practices had been invisible to me. I observed only one instance of writing by hand outside the classroom (when Dennis once wrote a note to Per). Non-screen reading was also very rare, although the environment contained written information, such as signs and notes. Claes was the only person who read the daily newspaper in print, and he sometimes offered the newspaper for the others to read, but no one was interested. Thus, although there were occasions of non-screen reading and writing, screen-based practices dominated by far.

Through this domination of screen-based literacy, online and offline settings were intertwined into one digitalised practice. The online/offline boundary was bridged as literacy chains weaved together events on both sides. In chain 3, for example, the chain starts with the idea (raised in an offline setting) of sending B a postcard. An online service is then used to create an offline postcard. B digitalised the card again by posting a picture of it on Facebook and then sending a photo of it to Joakim. Later, Selena brought the text back into the offline setting of the television lounge by reading it aloud from Joakim's screen. As a result of this literacy chain, B came to visit the group at the school, which means it produced tangible offline consequences.

#### Shared knowledge enabled co-creating literacy

By recurrently discussing literacy, the group members had developed an understanding of each other's literacy (dis)abilities and access to literacy resources, and they used this knowledge to co-create literacy events.

The group often talked (often laughing, like in chain 3 when Anette and Joakim laughed about choosing an inappropriate card) about literacy in terms of strengths and difficulties, comparing strategies and experiences. Through this meta-level of literacy, they had developed knowledge about who was better at spelling than reading aloud and so on. The shared knowledge also included who had access to which communication resources in terms of both screens and online tools, such as Facebook accounts.

In chain 1, Anette turned to me, Joakim and Selena for help before posting on Facebook. She turned to me when lacking the right words (e.g., harness) and later to Selena for choosing an emoticon. Joakim assisted Anette in her writing and corrected a misspelling. By stating that he was the proof-reader, he let me know that this event was part of a bigger practice. It was not just in this occasion that he proof-read something written by Anette; it was a standing agreement. Joakim, in his turn, showed me Anette's text to confirm some details. When I did not think he needed to change anything, he gave the phone back to Anette.

On the other hand, in chain 2 Joakim was the one asking Anette for assistance. He wanted to tell me the name of a medication, and he had found the name in writing online but he could not read it aloud. He then turned to Anette and asked her to read me the name. She struggled to pronounce the name and eventually gave up and, assisted by Dennis, passed me the phone to read the name myself.

The relationship, regarding shared knowledge, between the literacy chains is not arbitrary. It is not a coincidence that Joakim helps Anette in story 1 and that the roles are reversed in chain 2. Anette is better at reading than writing, and for Joakim the situation is the opposite. Similarly, Selena is better at reading than Joakim so he gives her his phone to read the postcard herself (in chain 3). They have learned to use each other's strengths to compensate for their own difficulties.

Thus, the result of the ongoing discussion about literacy is that the group members co-create literacy. They are actively using each other as resources, and the produced (or outspoken) text would not have been the same if produced by one singular group member.

## Discussion

A discussion about the identified characteristics of the literacy practices in terms of agency is presented below, followed by a methodological discussion and conclusions.

### *Literacy practices and agency*

Kagan and Simmons-Mackie (2013) emphasise that aphasia 'masks inherent competence', leaving the person with aphasia with a reduced agency. But the screen-based multimodality, and the literacy co-creation in which the participants compensated for each other's difficulties, gave them an opportunity to un-mask their inherent competences. Through these multimodal and co-created literacy events (linked into chains), the group could interact in ways that would otherwise have been impossible.

For example, in chain 1, Anette would have posted a text with errors (and maybe without any emoticon) if it were not for the assistance of others, and she probably would have spent more time creating the post.

In chain 2, Joakim's strategy to tell me the name of the medication was to use Anette's abilities. In that case, the screen itself (in addition to the assistance from Anette) became an important tool. Because Joakim's verbal abilities were limited, the fact that he found the name of the medication in writing online was crucial. Without the screen, he would not have been able to tell me the name of his medication.

Similarly, in chain 3, the combination of online resources (e.g., the postcard service), multimodality (e.g., B sending photos of the card to the group) and the co-creation (e.g., Anette and Joakim choosing the card and writing the text together and Selena reading the text out loud) led to the postcard being sent to B and eventually resulted in B visiting the group.

Thus, the online multimodality and the co-creation of literacy were decisive for the group. Without them, the group members would not have been able to communicate as competently. In this way, the literacy practices had an emancipatory meaning for the group members.

Previous research (Garcia Obregon 2002; Kjellén, Laakso & Henriksson 2017; Parr 1995) shows literacy practices are of relevance within aphasia rehabilitation. This study adds to that knowledge by emphasising the emancipatory aspect of screen-based literacy practices. Emancipation in relation to technology is often discussed within the field of alternative and augmentative communication (AAC) (see e.g., Koul 2011). None of the participants used any traditional AAC tool, but they all used digital screens in the same emancipatory way that AAC is meant to work. In contrast to many traditional AAC tools, the digital screens used within the group of this study (i.e., regular smartphones and tablets) were anti-stigmatising because of their similarity to the tools used by 'everyone else' (see also Moffatt, Pourshahid & Baecker 2017). These findings should be of value within fields such as universal design, because they highlight the importance of avoiding to develop excluding or stigmatising technology.

This study also adds knowledge about including environmental aspects when discussing technology and language disabilities such as aphasia. It is when the environment shifts from non-literacy practices to screen-based multimodal literacy practices that the agency may increase, enabling emancipation. Because this shift characterises the Swedish communication landscape in general, I argue the participants may experience increased agency in other settings, like their homes. At the same time, the school setting is unique, not least because it provides an opportunity to be a part of a group in which all members have aphasia. More research is needed to understand the transfer of literacy practices from settings like the school to other environments.

In terms of the relative model of disability (Söder 2013), emancipation can be understood as a reduced gap between the environmental characteristics and the participants' abilities. When the use of digital technology transforms a (formerly non-literacy) practice into a multimodal literacy practice, and when an individual with aphasia becomes part of a literacy co-creation practice, the disability caused by aphasia is reduced. With the increased agency follows a reduced disability.

### **Methodological discussion**

Ethnography is based on inductive and open ways of working, in which much is unspecified when the process starts (Hendryx-Bedalov 1998). Even if this article seems to report findings from a pre-formulated research process, that was not the case. The focus on literacy practices was not decided when I entered the field but emerged during my time at the school. Neither did I know that digital screens would be of such significance.

I chose a high level of participation (Spradley 2016) for several reasons. First, it would have been ethically questionable to place myself as a quiet bystander when the participants were seeking opportunities to improve their communicative skills (see also Antelius 2009). Second, it would be less efficient to be a bystander. I spent three weeks (except weekends) at the school, which is a rather short period for conducting ethnographic research. Antelius (2009) and Legg and Penn (2013) report the need of extra time and patience when studying people with communication disorders through ethnographic methods. In this respect, one could argue that I spent too short a time at the school. Thus, to make the most of my time at the school, I needed to be able to interact with the participants to clarify uncertainties or elaborate ideas throughout the field work. One clear disadvantage of spending a rather short period of time with the group, including the fact the group members already knew each other when I entered, is that I could not observe their literacy practices as they were initially formed. I therefore suggest further research over a longer period to capture how the practices develop over time.

A high level of participation within a group of people with communication disabilities entails the potential of being used as a communicative facilitator (Howe, Worrall & Hickson 2008). When having trouble communicating, the participants may turn to the researcher for help. A high degree of participation thus entails being part of the participants' strategic tools to manage difficult situations. I can relate to this, which is evident in all three literacy chains discussed in this article.

Some authors (e.g., Howe, Worrall & Hickson 2008) argue there are benefits if the researcher is a professional clinician in the studied field. My competence lies not in any clinical profession but in my academic background in computational linguistics, pedagogy, communication studies and disability research. I believe my non-clinical approach made it easier for me to connect to the participants. They knew I was not there to assess them but that I was a linguist and a researcher.

### **Conclusion**

To conclude, the collective and authentic literacy practices of the studied group were mainly characterised by the domination of digital screens and the online multimodal resources provided through them (bridging the boundary between online and offline settings) and the co-creation of literacy in which group members utilised each other's abilities to compensate for their own difficulties. These literacy practices were emancipatory and decisive for the group,

because they provided ways for the participants to un-mask their inherent competence. Thus, the multimodal and co-created literacy practices increased the participants' agency and reduced the disabilities caused by the aphasia.

The characteristics of the literacy practices within the group are not very different from the ones I engage in myself. As part of the highly-digitalised Swedish society, I can relate to many of the ways in which the group members use their screens and their online resources. But as I spent time with the group, I realised that the difference between my own literacy events and theirs is not how we interact, but rather on the level of agency and emancipation. For me, the screen provides additional tools that I sometimes prefer, but for the studied group, those tools are crucial.

### Competing Interests

The author has no competing interests to declare.

### References

- Antelius, Eleonor. 2009. "Would you like to use one of these or would you rather be able to talk?" – Facilitated and/or augmentative communication and the preference for speaking." *Scandinavian Journal of Disability Research* 11(4): 257. DOI: <https://doi.org/10.1080/15017410902909100>
- Bamberg, Michael. 2011. "Who am I? Narration and its contribution to self and identity." *Theory & Psychology* 21(1): 3–24. DOI: <https://doi.org/10.1177/0959354309355852>
- Barton, David, and Mary Hamilton. 2000. "Literacy practices." In *Situated Literacies: Reading and Writing in Context*, edited by David Barton, Mary Hamilton, and Roz Ivanic. London: Routledge.
- Barton, David, and Carmen Lee. 2013. *Language Online: Investigating Digital Texts and Practices*. London: Routledge. DOI: <https://doi.org/10.4324/9780203552308>
- Brockmeier, J. 2009. "Reaching for meaning: Human agency and the narrative imagination." *Theory & Psychology* 19(2): 213–33. DOI: <https://doi.org/10.1177/0959354309103540>
- Davidson, B., L. Worrall, and L. M. H. Hickson. 2003. "Identifying the communication activities of older people with aphasia: Evidence from naturalistic observation." *Aphasiology* 17(3): 243–64. DOI: <https://doi.org/10.1080/729255457>
- FIN (Folk High Schools' Informations Office). 2016. "The Swedish Folk High School." Accessed 11 April 2018. [folkhogskola.nu/globalassets/dokument-och-filer/folkhogskola\\_eng\\_engelska.pdf](http://folkhogskola.nu/globalassets/dokument-och-filer/folkhogskola_eng_engelska.pdf).
- Fram, Sheila M. 2013. "The Constant Comparative Analysis Method Outside of Grounded Theory." *The Qualitative Report* 18(1): 1–25.
- Garcia Obregon, Andrea. 2002. *Landscapes of competence: A case study of literacy practices and processes in the life of a man with aphasia*. The University of Arizona.
- Hammersley, M., and P. Atkinson. 2007. *Ethnography: Principles in practice*. 3rd ed. London: Routledge. DOI: <https://doi.org/10.4324/9780203944769>
- Hendryx-Bedalov, Patricia M. 1998. "Ethnography, An Introduction to Method and Application." *Journal of Children's Communication Development* 20(1): 19–25. DOI: <https://doi.org/10.1177/152574019802000103>
- Horton, Simon, Kathleen Lane, and Ciara Shiggins. 2016. "Supporting communication for people with aphasia in stroke rehabilitation: Transfer of training in a multidisciplinary stroke team." *Aphasiology* 30(5): 629–56. DOI: <https://doi.org/10.1080/02687038.2014.1000819>
- Howe, T. J., L. Worrall, and L. M. H. Hickson. 2008. "Observing people with aphasia: Environmental factors that influence their community participation." *Aphasiology* 22(6): 618–43. DOI: <https://doi.org/10.1080/02687030701536024>
- Kagan, Aura, and Nina Simmons-Mackie. 2013. "From My Perspective: Changing the Aphasia Narrative." *The ASHA Leader* 18(11): 6–8.
- Kjellén, Emma, Katja Laakso, and Ingrid Henriksson. 2017. "Aphasia and literacy—the insider's perspective." *International Journal of Language & Communication Disorders* 52(5): 573–84. DOI: <https://doi.org/10.1111/1460-6984.12302>
- Koul, R. 2011. *Augmentative and alternative communication for adults with aphasia: Science and clinical practice*. Emerald Group Publishing Limited. DOI: <https://doi.org/10.1163/9789004253131>
- Kovarsky, Dana. 2016. "A Retrospective Look at the Ethnography of Communication Disorders." *Journal of Interactional Research in Communication Disorders* 7(1): 1. DOI: <https://doi.org/10.1558/jircd.v7i1.27511>
- Kress, Gunther. 2003. *Literacy in the new media age*. London: Routledge. DOI: <https://doi.org/10.4324/9780203299234>
- Kress, Gunther. 2010. *Multimodality, a social semiotic approach to contemporary communication*. London: Routledge. DOI: <https://doi.org/10.4324/9780203970034>
- Legg, Carol, and Claire Penn. 2013. "A stroke of misfortune: Cultural interpretations of aphasia in South Africa." *Aphasiology* 27(2): 126–44. DOI: <https://doi.org/10.1080/02687038.2012.684338>
- Moffatt, Karyn, Golnoosh Pourshahid, and Ronald M. Baecker. 2017. "Augmentative and alternative communication devices for aphasia: The emerging role of 'smart' mobile devices." *Universal Access in the Information Society* 16(1): 115–28. DOI: <https://doi.org/10.1007/s10209-015-0428-x>
- Parr, Susie. 1995. "Everyday reading and writing in aphasia: Role change and the influence of pre-morbid literacy practice." *Aphasiology* 9(3): 223–38. DOI: <https://doi.org/10.1080/02687039508248197>
- Parr, Susie. 2007. "Living with severe aphasia: Tracking social exclusion." *Aphasiology* 21(1): 98–123. DOI: <https://doi.org/10.1080/02687030600798337>

- Sherratt, Sue, and Nina Simmons-Mackie. 2016. "Shared humour in aphasia groups: 'They should be called cheer groups'." *Aphasiology* 30(9): 1039–57. DOI: <https://doi.org/10.1080/02687038.2015.1092495>
- Simmons-Mackie, Nina, and Jack S. Damico. 1999. "Qualitative methods in aphasia research: Ethnography." *Aphasiology* 13(9–11): 681–7. DOI: <https://doi.org/10.1080/026870399401786>
- Simmons-Mackie, Nina, Roberta J. Elman, Audrey I. Holland, and Jack S. Damico. 2007. "Management of Discourse in Group Therapy for Aphasia." *Topics in Language Disorders* 27(1): 5–23. DOI: <https://doi.org/10.1097/00011363-200701000-00003>
- Söder, Mårten. 2013. "Swedish social disability research: A short version of a long story." *Scandinavian Journal of Disability Research* 15(1): 90–107. DOI: <https://doi.org/10.1080/15017419.2013.781961>
- Spradley, James P. 2016. *Participant observation*. Waveland Press Inc.
- Strandroos, Lisa, and Eleonor Antelius. 2017. "Interaction and common ground in dementia: Communication across linguistic and cultural diversity in a residential dementia care setting." *Health: An Interdisciplinary Journal for the Social Study of Health, Illness & Medicine* 21(5): 538. DOI: <https://doi.org/10.1177/1363459316677626>
- Street, Brian. 2004. "Futures of the Ethnography of Literacy?" *Language and Education* 18(4): 326–30. DOI: <https://doi.org/10.1080/09500780408666885>
- Swedish Internet Foundation. 2018. "Swedes and the internet 2018." Accessed 8 October 2018. [soi2018.se](http://soi2018.se).
- Taubner, Helena, Malin Hallén, and Åsa Wengelin. 2019. "Still the Same? – Self-Identity Dilemmas when Living with Post-Stroke Aphasia in a Digitalised Society." *Aphasiology*. DOI: <https://doi.org/10.1080/02687038.2019.1594151>
- Tregea, Shelley, and Kyla Brown. 2013. "What makes a successful peer-led aphasia support group?" *Aphasiology* 27(5): 581–98. DOI: <https://doi.org/10.1080/02687038.2013.796506>
- Vuorenpää, Sari. 2016. "Litteracitet genom interaktion [Literacy through Interaction]." Doctoral thesis, monograph, Örebro university.

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